Issue No.5 1994

NEWSLETTER OF THE NATIONAL FORUM ON AIDS AND CHILDREN

THE CORNISH EXPERIENCE

by Chris Bennetts

E arly in May this year it was brought to the attention of the Health Authority in Cornwall that there were strong rumours in the community that an ex-headteacher and convicted paedophile was HIV positive and now dying.

Because of patient confidentiality, this rumour could neither be confirmed nor denied, but because of concern for those in the community who might hear the rumour, it was considered necessary to set up a confidential helpline which could be staffed by health authority and social service employees, and which could offer help and advice to worried callers.

Knowledge that *The Sun* newspaper had planned to break the story in the national press meant that the planned press conference of the health authority, social services and LEA, had to be brought forward by a few days, in order that the news could be given to the Cornish public in a responsible manner.

Despite this, *The Sun* still published banner headlines on the following day of "Scandal of Perv Head with AIDS" and implied that a coverup of the story had only been averted thanks to their good selves, in a way that was geared more to raising fear and panic than to allaying concern.

Until then, HIV had not been an open issue for those young people who had been abused by the headteacher, and for some who had been abused, the nature of their abuse was not one which even now raised HIV in their minds at all.

However, there were one or two who needed someone to talk to, and there were some adults and young people who rang from various parts of the United Kingdom with very real concerns about HIV in connection with their own or their children's abuse, and which had no connection with the Cornish incident. This raised some concerns for the helpliners who were unable to offer more than an ear, a local GU clinic number in the area where the caller lived, and in some cases the ChildLine or Positively Women telephone numbers. All these callers were requesting anonymity and confidentiality and were reluctant to involve social services in their areas.

The helpline ran on a three-tier system. The first tier was staffed by nurses who had had extra HIV/AIDS training. They dealt with all calls which required specific HIV information. Any call which was also linking in sexual abuse was passed to a second tier of social workers with expertise in the area of abuse. They in turn passed any call which posed the issue of HIV risk to past or on-going sexual abuse, and which asked for counselling around antibody testing to the third tier, myself. This staged approach worked well and the level of personal support between team members was very strong.

When some weeks later, the man eventually died, the media once more tried to resurrect the issue in the community. However, no further calls were received from the public and it has to be assumed that for the present at least, the needs of the community were met as well as possible.

Incidents like this however, do raise interesting ethical and managerial questions for health authorities and social services:

- should health authorities disclose the HIV+ status of a patient who is a known paedophile?
- should social services contact parents and children to inform them of "suspected" HIV+ status?
- are we prepared and trained to talk with children about their concerns of an HIV risk following sexual abuse?

The youngest caller was nine years old. Children who ask for help deserve a considered response to what is a real concern.

Children who have been sexually abused frequently only tell enough of their story to ensure that the abuse stops. It has been my experience in all sexual abuse referrals, paedophile or other, that an HIV concern always prompts the child or young person to give more of the story. We should not assume therefore that "only low-risk activity has occurred". We need to listen to the children and constantly attempt to meet their needs.

Chris Bennetts is the Coordinator, Sexual Health Unit, Cornwall Health Promotion Unit, Tregolls Road, St Clement Vean, Truro TR1 1NR (0872 74242, ext. 7291). She is one of the authors of the book AIDS: the hidden agenda in child sexual abuse (Longman, 1992).

NATIONAL FORUM ON AIDS AND CHILDREN

The National Forum on AIDS and Children brings together organisations concerned with children infected or affected by HIV, from both the voluntary and statutory sectors.

The Forum aims to promote the interests and welfare of children and young people in relation to HIV/AIDS issues by:

- □ promoting an effective voice for children,
- providing a national resource and data-base,
- disseminating information about good practice,
- promoting research and train-
- identifying un-met needs and promoting service development,
- campaigning and lobbying, representing members' views to government, media and outside bodies.

ChildAIDS, the newsletter of the National Forum on AIDS and Children, is published quarterly. Views expressed in the newsletter do not necessarily reflect those of the Forum as a whole.

Contributions of articles and materials for review are welcomed and should be sent to the editor, Neil Orr, at the following address.

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Published for the National Forum on AIDS and Children by:



Registered Charity No. 258825 This issue published September 1994, with support from Mercury Phoenix Trust and Crusaid.

Planning HIV Services for Children and Families: Looking to the Future



National Forum on AIDS and Children conference, 28 November 1994, New Connaught Rooms, London WC2, 10.00 am - 4.30 pm.

A major one-day conference organised by the National Forum on AIDS and Children in association with the National AIDS Trust and the National Children's Bureau. This event will address the twin themes of the International Year of the Family and World AIDS Day 1994 "AIDS and the Family". It will focus on how the statutory and voluntary sectors can develop effective and integrated services for children and families affected by HIV in the future. Speakers will include:

Baroness Cumberlege (Parliamentary Under-Secretary of State for Health) Kathleen Marshall (Glasgow Caledonian University) Mike Jarman (Director, Children's Service, Barnardo's) Chris Batty (Lead Officer HIV/AIDS, Leicestershire County Council) Terry Cotton (Head of Purchasing, Westminster Social Services)

The cost for Forum members (and National Children's Bureau members) is £111.62 (including £16.62 VAT), £82.25 (including £12.25 VAT) for voluntary members. For non-members the rates are £141, and £94.00 for voluntaries.

Further details from the Conference Office, National Children's Bureau, 8 Wakley Street, London ECIV 7QE (tel. 071 843 6041, fax. 071 843 6039).

Joining the Forum

Since the National Forum on AIDS and Children established a formal membership scheme earlier this year, 58 organisations have affiliated. As well as receiving ChildAIDS newsletter and other mailouts, members have priority in attending Forum events. The annual membership fee is £30 for statutory and national voluntary organisations, and £15 for small voluntary organisations and individual associates. Those who wish to subscribe to the newsletter without joining the Forum can do so for £15 for four issues. Please make cheques payable to the National Forum on AIDS and Children. Members to date include the following:

Action with Young Carers, AVERT, Barnardo's Family Placement Services, Barnardo's Broad Street Project, Bradford Social Services, Bromley Hospitals Trust, Cheviot Children's Centre, Children in Wales, Children in Scotland, Church of Scotland Board of Social Responsibility, Derbyshire County Council, East London Childcare Initiative, George House Grandma's, Great Ormond Street Children's Hospital, Greenwich Family Link, Hammersmith and Fulham Social Services, Harrow Social Services, Health Promotion Agency for Northern Ireland, Hereford and Worcester County Council Social Serivces, Hillingdon Social Services, Hinchingbrooke Health Care NHS Trust HIV Support Team, Hounslow Social Services, Information Unit on Addiction, Institute for the Study of Drug Dependence, Lambeth Social Services, Leicester County Council Social Services, London Ecumenical AIDS Trust, London Borough of Haringey, London Lighthouse, Merton Council Social Services, Mid Kent Social Services

Homefinding Team, Mildmay Mission Hospital, National Association for the Education of Sick Children, National Children's Bureau, National AIDS Trust, Newcastle Social Services HIV/AIDS Project, North West Anglia Health Promotion Service, Northamptonshire social services, Oasis AIDS Support Centre, Paediatric AIDS Resource Centre, Positive Youth, Positively Women, Positively Partners/Positively Children, Riverside Community Health Care, Royal Free Hospital School of Medicine Dept. of Public Health, Salvation Army, Save the Children Fund, South Essex Health Authority AIDS Information Centre, South Glamorgan Health Authority Dept. of Public Health, Southern Derbyshire Community Services NHS Trust, Surrey Social Services, Tameside and Glossop Community and Priority Trust, Terrence Higgins Trust, Thomas Coram Foundation for Children, Tower Hamlets Social Services, Trinity House Resource Centre, Waltham Forest HIV Unit, Westminster Social Services Family Link Scheme, Women and Medical Practice.

HIV EDUCATION

Tew legal requirements on HIV education in England and Wales came into effect from August 1994. Section 241 of the 1993 Education Act requires all maintained secondary schools to provide sex education, including education about HIV/AIDS, to all registered pupils. However it also removes HIV/AIDS, STDs and non-biological aspects of sexual behaviour from the National Curriculum, while giving parents the right to withdraw children from any sex education not included in the National Curriculum.

The Department for Education has issued guidance to schools on sex education in the context of the new legislation. There has been some confusion about the implications of this guidance for the ability of teachers to provide confidential advice about sex and contraception to individual pupils. The guidance states that if a teacher believes that a pupil "has embarked upon, or is contemplating, a course of conduct which is likely to place him or her at moral or physical risk or in breach of the law" the teacher should inform the head teacher, who should in turn arrange "for the parents to be made aware, preferably by the pupil himself or herself (and in that case checking should be done)". There is a danger that teachers will feel unable to offer confidential advice if a pupil expresses concerns about HIV, and that pupils will be discouraged from seeking such advice.

However, there has been no change in the law and there is no legal duty on a teacher to inform parents of matters which a child has confided in them. The guidance itself is advisory and is not legally binding. It will be for individual schools to decide how they will deal with confidentiality.

Copies of DFE Circular 5/94, Sex education in schools, can be obtained from the DFE on 071 925 5555. The Sex Education Forum has produced a Factsheet on the changes, available from Sex Education Forum, 8 Wakley Street, London ECIV 7QE (tel. 071 843 6000).

The National Forum on AIDS and Children has been asked by the Local Authority Associations' Officer Working Group on AIDS to assist with a short term project on children infected and affected by HIV in schools. It is proposed to focus on one local area to assess how different parts of the schooling system might respond to the needs of such children. We would be interested in hearing of any relevant experiences schools have had, and seeing any policy guidelines that have been developed.

Contact Neil Orr at the National Forum on AIDS and Children, or Les Woods of the LAA-OWGA at the Local Government Management Board, Arndale House, Arndale Centre, Luton, Beds LU1 2TS (0582 451166).

Two weeks with the Queen

he National Theatre is currently staging the play Two weeks with the Queen, adapted for stage by Mary Morris from the best selling novel by Morris Gleitzman, and directed by Alan Ayckbourn. In the play Colin, the 12 year old hero, is packed off to London from Australia after his brother becomes ill with cancer. He struggles to come to terms with this illness and adults' reactions to it, being helped along the way by two gay men he meets, one of whom has AIDS. As well as dealing sensitively with the issues of illness and death, the play is often very funny.

Two Weeks with the Queen is aimed at young people aged 9 years and upwards, and is due to run until March 1995. A background pack has been produced for teachers.

Further details from: Jenny Harris, Head of Education, Royal National Theatre, South Bank, London SE1 9PX (tel. 071 928 2033).

UK HIV STATISTICS

By July 31st 1994, there had been 646 reports of children being born to HIV positive mothers in the UK (387 in the Thames Regions, 108 in the rest of England, Wales, and N. Ireland, and 151 in Scotland). Of these, 252 are known to be infected, 205 are uninfected, and 189 are of indeterminate status.

In addition 298 children (aged 14 or under) in the UK have become infected with HIV via infected blood or blood products, and two more have become infected in undetermined ways. Out of a total of 552 confirmed cases of HIV in children aged 14 or under, there have been 117 deaths. 232 of these are now aged 15 or over, or were at the time of death.

Of the 127 UK cases of AIDS amongst children infected with HIV via their mothers (as of 30 June 1994). 79 children are black, 30 are white, 2 are Asian or oriental, and 16 are classified as other, mixed, or unknown.

National Study of HIV in Pregnancy, September 1994; Public Health Laboratory Service Quarterly AIDS and HIV figures, 18 July 1994; Communicable Disease Report, 15 July

ANTENATAL SCREENING RESULTS

The latest results of a survey of HIV amongst pregnant women show an increase in the rate of HIV prevalence in London in this group. Blood samples collected for antenatal screening have been anonymously tested for HIV since 1990 in 40 centres in London, Greater Manchester, West Yorkshire, and adjacent non-metropolitan areas. Outside of London there has been no increase in seroprevalence of HIV-1. The rates were 0.007% (1 in 14530) in non-metropolitan areas and 0.011% (1 in 8790) in metropolitan areas outside London.

In London centres however the rate has increased from 0.18% (1 in 560) in 1990 to 0.26% in 1993 (1 in 390). Amongst pregnant women aged 20 to 30 in London, 0.03% (1 in 335) were HIV-infected. According to figures published in the Independent, the highest rate in London is in Newham (1 in 196), compared with one in 593 in Hackney, and one in 1,322 in Tower Hamlets.

Communicable Disease Report, 16 September 1994; Independent, 21 June 1994.

WORKING WITH THE MEDIA

The National AIDS Trust have drawn up new policy Guidelines on working with the media for agencies involved with children, families and HIV/AIDS. Huw Meredith of NAT outlines the thinking behind them.

The Guidelines highlight some of the pitfalls faced by agencies who come under pressure to produce media material, and sets standards regarding confidentiality, obtaining primary interview material, and use of case studies.

1994 is the International Year of the Family, and this has been taken up by the World Health Organisation's Global Programme on AIDS to set the theme for this year's World AIDS Day - AIDS and the Family. The strength of the Day is as a public relations opportunity, focussing the attention of the general public on the global impact of AIDS, the numbers of people living with HIV, and those who have died of AIDS. The family theme shifts the focus, for this year, from those who have the virus, to those who are affected by it - parents, siblings, grandparents, partners, carers - "the definition of family embraces personal relationships and social families of every kind".

This gives an opportunity for issues to be explored and publicity given to work with affected children and families which might otherwise have to take a back seat. The downside is the danger that agencies may be swamped by requests from the media which they are not ready to meet. This may lead to a real conflict of interest: do we opt for publicity at all costs, or do we hold out for higher standards at the risk of losing out on a valuable chance to publicise our work and maybe boost our income?

Experience in Edinburgh, where supportive work with families has developed over a number of years, points up this dilemma. "Journalists do not appreciate the level of stigma and real danger that families with the virus face," says Sarah Morton of Children in Scotland. "They seem to

think that we are blowing the issue out of proportion. But where a few HIV positive parents have got involved, with support, it is very difficult to know how much good this does a family. Whilst there are some responsible journalists, it is very difficult to know what their agendas are, and what use they will put the material to."

Worryingly, Sarah adds that "We have been refused any coverage of some events because we haven't produced a family for the media to interview."



"I can't educate you at my children's expense" (mother of child with AIDS)

The Guidelines urge agencies to question the premise that the story cannot run if primary material is not made available, and to have material ready prepared which promote the agency clearly in the way they are happy with. This might include producing a factsheet stating what they do, or drawing up a set of policy statements on issues they might be asked to give a view on.

From the other side of the fence, Sarah Jackson, Media Officer at Barnardo's, reports that "Sometimes social workers who are used to working with sensitive issues like child protection can be slow to take advantage of media opportunities. From the Press Office, this can seem to us that they're being a bit overprotective".

Certainly the demands on agencies to provide interviews and primary material are constantly increasing. To some extent, awareness of the particular stigma and prejudice surrounding HIV and AIDS does protect families and agencies from some of the worst excesses of media intrusion, as compared with experiences like that of a parent of a child with another terminal condition who received over 600 enquiries to her home telephone from journalists seeking a story. It is a sad aspect of modern society that the fact that a person is ill, seems to makes them public property, rather than guaranteeing privacy and respect.

In any case, it is very likely that there will be a mismatch between the operational standards of workers, and those of the media, over issues such as confidentiality and authenticity. The Forum's own Neil Orr, on informing a researcher that it would not be possible to provide a baby with HIV to film, was told "Well, I suppose we could use a child without HIV, as all babies look pretty much the same".

Although agencies like Save the Children Fund have issued practice documents on dealing with the media and use of photographic images, there appears to be little if any guidance on ethical standards regarding the use of children in publicity material. The NAT Guidelines are an attempt to bring together best practice from workers' experience, to encourage agencies to develop their own media policies and strengthen their hand in negotiating higher standards from the journalists and researchers they deal with.

But as the Guidelines conclude: "We all have a responsibility to direct media attitudes along more constructive lines. As well as setting high standards for current practice, it is important to promote more positive and innovative approaches which will allow young people to make their voice heard without losing editorial control over the message."

Copies of 'Children, HIV and the Media: Policy Guidelines for Agencies' are available from Huw Meredith at the National AIDS Trust, 80 Newington Causeway, London SE1 6EF. Tel: 071-972 2887.

B arnardo's in partnership with Tayside Regional Council have set up the Flexible Care and Planning Service Project to support families who are affected/infected by HIV/AIDS. This has been in response to the lack of specific services which address the needs of these families. The Project has two focuses in terms of helping families:

- To provide a Planning Service the Project will assist families in coming to terms with what HIV/AIDS means and to help them to start discussing and planning for the future in both practical and emotional terms. This is to be done through ensuring plans are made for the future care of children and through Life Story/Memory Store work to ensure children have a clear record of their parent/s.
- To provide practical support through the provision of a respite care and volunteer scheme which can respond flexibly to the needs of families.

There are some major differences which set this scheme apart from foster care or other respite care schemes. Carers are being asked to be very flexible, both in the type of care they provide and the times. Because of the nature of the illness, carers will be providing respite at very short notice as well as on a planned basis.

Respite will also take very different forms from the traditional overnight/weekend break to providing day/after school care. It may mean that the carer stays overnight in the child's home.

We are asking carers to develop relationships, not just with the child/ren but with the parents as well because they are going to need support. This also allows for a continuity and consistency of care for the children which is obviously very important. This does mean that carers may be contacted at different times by parents looking for help.

In order to support carers, initially all carers will be receiving training around the impact of HIV/AIDS on families, confidentiality, loss and bereavement and so on. This is only viewed as a starting point, with further training to be provided in consultation

with carers. Alongside that, the Project will be running a regular carers group which is seen as being an integral part of its work.

To conclude, the Project aims to provide a service to a group of children and young people who until recently have not had access to anything. In doing so we hope to work in partnership with families and carers and ensure that children are helped to cope with some very difficult issues.

Catriona Walker, Project Leader, HIV/AIDS Project, Barnardo's, 235 Corstorphine Road, Edinburgh EH12 7AR (tel. 031 334 9893):

In partnership with Lothian Region Social Work Department, Barnardo's are developing a respite care service for families affected by HIV/AIDS. The nature of the work requires that carers work closely with parents to ensure that they are alleviated of any concerns regarding the welfare of their children in their absence. In a planned way, every effort is made to ensure that children's lives are not unduly disrupted by a separation from their parents. Routines are observed, likes and dislikes established and preparatory visits to both homes organised wherever possible.

Carers are required to be flexible, as a placement can range from a regular weekend short break, to the other end of the spectrum where carers may be looking after children for five to seven days a week. We now have a pool of carers who can offer this service, and several children and families are already benefiting.

Respite care is also becoming an increasingly central part of the support the project offers to all our foster and adoptive families. This has necessitated the recruitment of additional families specifically for this task.

Patty Ironside, Respite care co-ordinator, Barnardo's Family Placement Services, 6 Torphicken Street, Edinburgh EH3 8JQ (tel. 031 228 4121).

pite care for families affected by

The following three articles are based on contributions to a National Forum on AIDS and Children meeting on respite care held in London in May 1994. Below, Christine Lenehan describes Families Together, an innovative family-based respite care scheme in Tower Hamlets working with children who have significant disability. Much of their experience is applicable to the HIV field, demonstrating the need for those developing HIV services to learn from good practice elsewhere. Juliet Ramage and Dee Donnelly then describe new services in Westminster and East London respectively.

A disability perspective

R espite care schemes for children with disabilities took off in the 1970s as an attempt to provide good services for children without institutionalising them. One of the problems is that they took off in areas which were traditional suburbs, depending on middle class hinterlands to recruit carers from. Families Together couldn't do that in Tower Hamlets; its hinterland is Hackney and Newham where there is not a middle class, or not much of it.

What Families Together had to do in 1987 when it was asked by the Borough to run the service was to prove it could do two things: run an inner-city respite care service using inner city carers, and offer a relevant, accessible service to a Borough whose child care population is 60% Bangladeshi. It would have been fairly easy to run a white service, borrowing carers from outer London, but that wasn't what we intended to do.

Within the first three years, the project was able to meet the minimal premises set for it, and it continues to do so. Over 90% of our carers live within Tower Hamlets, and the population of children who use our services include 46% who are Bangladeshi. Our carers also reflect the Borough's trends.

Research on disability services clearly shows that children from black and minority ethnic groups miss out. Across the country there are very few services that are representative of their needs.

An issue for us is using white middle class assessment systems to recruit carers that are based in the inner cities. We had to undo the assessment process at the beginning and look at basics: what can this person positively offer a child in their care, and work assessment around this, partly because we felt that traditional expectations were not going to be met by our carers.

A simple example is housing. In Tower Hamlets, 80% plus of the borough's

housing stock is publicly-owned, most of it fairly poor, and overcrowded. Our children live in that, our borough still allocates children to seven storey blocks of flats, and our carers' housing reflects that of children. Although it's very easy convincing the housing department that children can live seven storeys up, it's not very easy convincing the foster panel that people who look after children can live seven floors in the sky.

The majority of our carers, certainly our white and African Caribbean carers, are single parents living on income support, in local authority housing, and whose histories reflect the experience of living within the local area. The project has had to adapt to that. For example, carers are often paid monthly; our carers have children from Friday to Sunday and they get paid on Monday when they come in. We also need quite big equipment stores. Our families don't have spare beds, bedding or stairgates. We have to be able to supply these and to get over the hurdles that would otherwise stop our families caring for children in their care.

A complicated issue for us was getting the service to Bangladeshi families to work. We knew from the outset that we were going into an eastern community with a western idea of care expecting them to agree with it. We went in with a community development approach, talking with people about what they needed to enable them to keep their disabled children at home. We also had to work with men in the community to make it acceptable for their wives to be carers, and for their children to use respite care. We had to make it clear that we were not a white service that happened to have Bangladeshi carers and children, but that we were a multicultural service.

Another thing we faced was western values on assessment. The first time we took a Bangladeshi carer to a foster panel, members of the panel asked

whether or not it was acceptable that somebody did not know their prospective husband before marriage, showing a phenomenal lack of cultural understanding.

We set up monitoring and evaluation programmes from the outset, before the first child got a placement, before the first carer was recruited. We have set clear goals and objectives for services, both in terms of numbers and aims, but also in terms of quality standards. We have found particularly useful four simple quality indicators:

- Flexibility and availability of service: how long does it take to provide a link for a child? How quickly can a project respond in crisis. How responsive is the service in situations which do not fit into usual categories?
- Representation and presentation: matching what a project aims to do against a demographic picture of its community. Is the service available to the communities that need it most?
- Quality of linking: what is the preparation, how do we prepare children or parents for changes in their family?
- Quality of care: if you have placed a child are you sure that the quality is up to standard? It is common in the disability field for respite care to be provided in the child's home, rather than the carer's home, either because some children are more comfortable in their own home, or because they are very young- with a child under two I think you'd need a very good reason for taking the child out of the home.

In summary respite care can work well, but only when it offers a specific focused service for a specific focused group, with good standards. It cannot answer all the problems.

Christine Lenehan, Barnardo's Families Together, 2 Paradise Row, London E2.

Westminster Family Link Scheme

The scheme for families affected by HIV is part of a wider disability and special needs family link service. I see our scheme as a branch of that which often overlaps. The scheme's aims are:

- To enable families affected by HIV to stay together as long as possible by the provision of easily accessible short term care.
- To provide a flexible support service which can respond to individual needs of different families.
- To provide services that can form a continuum of support ranging from respite help (e.g. babysitting) through to carers looking after children on a full-time basis while plans are made for their permanent placement. The service recognises that family's needs and circumstances change over time.

Who can be approved as carers?

Care can be provided by individuals, couples, or families. Approval is based on the ability to offer good quality child care. Applicants are accepted irrespective of sexuality, disability, race, culture and language.

The method of approval and expectations of carers varies according to the service they offer. Some people would like to offer just a few hours care on a voluntary basis, some people need to be fully assessed as foster carers, and others prefer to be self-employed rather like childminders. Relatives and friends may fit into any of these three categories.

The minimum checks are that everyone has to have a police reference, medical reference, personal referees taken up, all must receive training, and all must be interviewed. The aim is to be as unbureaucratic as possible, while recognising our responsibilities under the Children Act.

Tasks required range from befriending, to collecting children from school, to caring for children over the weekend, to actually caring for children while they await a permanent placement. There is flexibility built into the scheme. Once linked with a family or families, the link carer's commitment is to those families. Linking carers to families rather than having a pool of carers ensures continuity for the family and the availability of link carers to respond to a family's changing needs.

How do families access the service?

Referrals may come from a wide range of sources. Families coming forward may be known to a variety of agencies but not social services, and others may be known to social work teams. There is a big debate about whether a social worker needs to be allocated to every family accessing the service. If you just require a few hours babysitting you may not need a social worker. It is important though to identify a key worker from within the family's network and try not to overload them by having too many professionals going in. There are times when a social worker will have to be allocated, when there are child protection issues or if the package of care does involve overnight or a substantial package of care.

Have you got time for children?

We need carers to look after children with disabilities and special needs. You don't have to have special qualifications but you must enjoy taking care of children and be willing to attend preparation and training sessions. Family link matches carers with families of children with disabilities to enable parents to have a break. Support is also given to families experiencing ill-health.

Carers receive payment training and support. If you live in or near Westminster and can spare 2 hours, 2 days or more, give us a ring on 071 262 7424.

The text of Westminster's recruitment advert

Where should respite care services for HIV be located?

There isn't one model. I am based in a special needs team for children with disability, and there are advantages and disadvantages to this.

Disadvantages are that HIV and AIDS shouldn't necessarily be associated with disability, and I also feel that respite carers are traditionally the most poorly paid carers. This wasn't a model we wanted to embrace. We have tried to get respite carers in Westminster to have parity with foster carers in Westminster, who are paid a weekly fee and maintenance for look-

ing after children. The advantages are that the disability field was where the pioneering work in partnership and delivering foster care in a non-stigmatising way started.

Over time I feel that respite child care services won't be limited to disability or HIV. They will grow to encompass people with mental health problems, families living with sickle cell and a whole range of other families who also need shared care or respite schemes. Inevitably, HIV services are going to become mainstream, and I feel that aligning them in Westminster with the good practice that has been developed in the disability field is a good model.

Recruitment of carers

We have had a recruitment campaign joining forces with my colleagues in disability. We had 112 responses and 52 of those people have now attended information meetings. Of the 52, 21 were white, 5 Asian, 11 African and 15 Afro-Caribbean, all from within Westminster or neighbouring boroughs. Of these 52, 17 said they were only interested in caring for a child with a disability, 6 only in HIV, and 26 in either disability or HIV (three wanted more information before they made up their minds). My final message is look and you will find the carers. People aren't as frightened of HIV as we think, and if 26 of those 52 people say that they will care for children with disabilities or with HIV, there is good reason for tapping into family-based respite care schemes for disability for our resources for the future.

Juliet Ramage, Respite Care coordinator (families affected by HIV and AIDS), Family Link Scheme, Westminster Social Services, 155 Westbourne Terrace, London W2 6JX (tel. 071 262 7424).

DEPARTMENT OF HEALTH CONSULTATION PAPER

In England and Wales, Children Act regulations' define respite care as any placement involving a stay away from home of more than 24 hours. A preplanned series of respite care placements is treated as a single placement in these regulations, but if placements exceed 90 days in any one year (or more than four weeks at a time), each successive placement is regarded as a new arrangement requiring the local authority to repeat planning and other arrangements.

These arrangements have been criticised for being inflexible and overformalised, and in response to these concerns, the Department of Health issued a consultation paper in August 1994 on Short-term placement (respite care) of children. The Department acknowledges that "some easement of the Regulations... would make them more applicable to the short-term situation". They proposing to extend the maximum duration of a single placement in any one year to 120 days, and to make other changes to the timing of reviews, and to the assessment of health care requirements of children.

Copies of the consultation paper are available from Department of Health, Community Services 3C, Room 236, Wellington House, 133-155 Waterloo Road, London SE1 8UG. The formal consultation period will end on 31 October 1994 after which the regulations will be amended.

Department of Health (1991), The Children Act 1989 Guidance and Regulations, volume three: family placements.

SCOTLAND

The Scottish Office's Scotland's children: proposals for child care policy and law (1993) recognises that "Children with life-threatening conditions and their families can benefit particularly from respite care" and commits the Government to reviewing the relevant regulations "to prescribe a framework for provision and so ensure a consistency of approach by local authorities".

This Information Sheet published by the National Forum on AIDS and Children, 8 Wakley Street, London EC1V 7QE (tel. 071 843 6000).

East London Childcare Initiative

The East London Childcare Initiative has been funded by the Department of Health and North Thames Regional Health Authority to provide support to mainstream children and families services in four London Boroughs: Newham, Hackney, Tower Hamlets and Waltham Forrest. The aim is not to do direct work, but to help the existing services to respond more flexibly to families affected by HIV in East London. We will be establishing a bank of carers across the four boroughs able to offer flexible childcare.

Estimates of the numbers of families affected by HIV range from 100 families over the four boroughs, to about 60 families actually being worked with in mainstream social services at the moment. We certainly know that there are many families who aren't being worked with in the mainstream, although they may be known to hospitals. We know that women from East London do go as far as St Mary's Hospital (on the other side of London), and that they travel great distances. Many families are still reluctant to use locally based services.

In East London, the great majority of the families we'll be working with will be black families, and specifically African families, many of them asylum seekers. Both of our project workers are African women, and can hopefully tap in to existing communities. A main task for us is going to be outreach into areas where the notion of fostering and respite care needs to be explained in some way. We're already getting quite good feedback that if we make information available, people are interested in offering care.

We are currently involved in trying to dovetail recruitment procedures, assessment procedures, weights, allowances, etc. The boroughs will need to agree a consistent set of payments and conditions for newly recruited carers.

Our steering group, which is chaired by one of the directors of social services, includes representatives from the four boroughs as well as service users, which is a new development. LEAN (London East AIDS Network), which is based in Newham, has a women's development worker. Part of her brief is to recruit and train users to come on to the steering group. At the moment, five women have been trained in such things as how to deal with meetings full of professionals and the language they use. They bring to the steering group their own experience of getting and not getting services. They are keen to be involved in recruitment.

We want to provide carers who can provide flexible care right the way through to more permanent planning. We want to involve the parents as much as we can in the choice of those carers, and we want to encourage parents who may know of carers to come forward.

BAAF (British Agencies for Adoption and Fostering) are developing a new flexible "Form F" (the form given to assess a foster carer). This has been designed in the light of moving away from the traditional idea we have of carers being quite unknown to families, to thinking of friends, extended family members, and kinship networks. BAAF have agreed to pilot this with ELCI.

Dee Donnelly, Project Manager, East London Childcare Initiative, 100 Shepherdess Walk, London N1 7JN (tel. 071 250 1390).

Note on language: As Christine Lenehan noted "The disability field is now moving away from the language of respite care. The dictionary defines respite as laying down a burden; we do not feel that our children our burdens". The Department of Health Social Services Inspectorate has also preferred the use of the term "short-term breaks", noting that "respite has negative connotations because it has tended to put the focus mainly on provision for carers" rather than on the needs of the child or adult being cared for. See DoH SSI (1993), Guidance on short-term breaks.

CARING FOR CHILDREN AND FAMILIES AFFECTED BY HIV AND AIDS

Children in Scotland/National Foster Care Association Conference, 6th May 1994, Glasgow

ow can we care for children whose parents are affected, or have died from a disease surrounded by stigma and taboo? How can we ensure that young people in our care grow up with the skills required to protect themselves? This conference was set up for foster carers and social workers to explore these issues, whether they are caring for children directly affected by HIV, or for children growing up in a world where HIV will be an issue for them in their own sex lives.

The conference was chaired by Mary Hepburn, Consultant Gynaecologist in Women's Reproductive health at the Royal Maternity Hospital in Glasgow, who set the scene by explaining the prevalence of HIV in Scotland.

Gerry O'Hara from Lothian Regional Council provided the keynote address. He discussed some of the issues for foster carers in providing the kind of flexible support for HIV affected families which has been developed in the Lothian Region since the early eighties.

The children are never formally received into care under this system, and the mother continues to look after them as much as possible. The system requires a tremendous amount of support, with a range of care from short-term to longer term

by Sarah Morton



available, and often needed at very short notice if the parent falls ill. All Lothian Region's carers have to be prepared for the fact that they may be caring for HIV infected or affected children without their knowledge, as the status of all clients is not known. However, carers volunteer for cases where HIV is known to be an issue, although the families affected by the virus in Edinburgh are often also affected by a range of other factors including drug use and poverty.

Some carers go on to adopt the child after the parent's death "the attachment just builds and builds. In some cases we are losing some of our best carers because they're claiming the kids" says O'Hara.

Jean Morrison discussed the issues that children face if their parents dies, and some of the supportive strategies that can be used to help children communicate their feelings. She described the kinds of behaviour that children who are bereaved may

show, for example loud crying as a sign of protest, withdrawal as a sign of despair, and detachment. Ms Morrison emphasised the importance of consistent support for children during bereavement in order to prevent the experience from causing them difficulty into their adult life. In particular adequate support and honest information are needed, as well as good parent substitutes.

Cathie Wright from the Brook Advisory Centre gave a presentation on talking to children and young people about sex and sexuality. She discussed some of the difficulties that we may feel as parents or carers in opening up the topic of sex. This will be related to the messages we got as children from adults about sex. However, research indicates that the more information children and young people have about sex, the less likely they are to have sex early and the more likely they are to protect themselves against unwanted pregnancy as well as HIV.

Teachers, parents and carers all have a role in educating children and young people about sex, but they need to be properly supported with information advice and policy. This enables them to do a better job and not to be afraid that their efforts to answer children's questions honestly will not be met with a barrage of public criticism.

Launch of the Tayside Forum on Children and HIV

Children in Scotland initiated a collaborative multidisciplinary HIV Forum to look at issues for children affected by the virus in Tayside Region. There are a proportionally high number of families affected by the virus in the region, and it has been established to allow those who work with these families to meet. Teachers, social workers, nurses and others may be isolated and unsupported when working with a family affected by the virus, and expertise is being developed in pockets. There is a need for all those working with children to have access to the experience and expertise that has been developed, and to meet and to exchange views, experiences and make recommendations for policy and practice development.

The first full meeting of the Forum was held on 26th May 1994, and focused on the Scottish Office Guidance on Children and HIV. Professionals got together to discuss a range of issues in

their work with affected families, including confidentiality and testing; adoption and fostering; prevention work and day care. One of the important aspects of the event was in creating a dialogue between those working in HIV adult agencies, and those in children's agencies.

The meeting also discussed the role of the Forum in Tayside, and what could be covered in future meetings of this kind. There was overwhelming support for the establishment of the Forum, and suggestions were made for the group to be involved in supporting developments in the region. These might take the form of developing model confidentiality guidelines, promoting training, or influencing the regional council.

Contact: Sarah Morton, Children in Scotland, Princes House, 5 Shandwick Place, Edinburgh EH2 4RG (031 228 8484).

MOTHER-TO CHILD HIV TRANSMISSION

Caesarean section

study based on data from the European Collaborative Study suggests that caesarean section may reduce the risk of mother-to-child HIV transmission by approximately a half1. The study looked at the effect of different modes of delivery in 1254 HIV-infected mothers, and estimated that a vertical transmission of rate of 18% in children born by vaginal delivery compared with a 9.7% risk of transmission after caesarean section. 12 caesarean sections would therefore have to be carried out to prevent infection in one infant.

The authors note that "Mother-tochild transmission of HIV may be reduced by caesarean section delivery because direct contact with contaminated blood and cervical secretions is avoided during the infant's passage through the vaginal birth canal". However other studies have not found such a clear link. and given the possible implications of a caesarean for the mother's health, the authors argue that the evidence is not conclusive enough to justify caesarean sections becoming routine practice for mothers with HIV. It is proposed to carry out a major trial through the European

Collaborative Study to further evaluate the effects of mode of delivery on HIV transmission.

Meanwhile discussions are continuing about the implications of the ACTG 076 trial which suggests that zidovudine (AZT) may reduce the risk of HIV transmission. In the US. recommendations have been issued to clinicians by the US Public Health Service². In the UK, AZT has not been licensed for use to prevent vertical transmission though it is available to pregnant women on an individual "compassionate release" basis. Many clinicians feel that there is a need for long-term follow up of the women and children in ACTG 076, and for further trials, before any firm recommendations can be made about the use of the drug in pregnancy.

Vitamin A deficiency

A study from Malawi suggests that vitamin A deficiency may increase the risk of mother-to-child transmission of HIV³. Amongst 338 mothers with HIV, the rates of transmission varied from 32.4% in the group with the lowest levels of vitamin A to 7.2% in the group with the highest vitamin A concentrations.

Both pregnancy and HIV infection are associated with vitamin A deficiency. As well as stimulating the immune system, vitamin A helps to maintain the integrity of mucosal surfaces. Its deficiency may increase the susceptibility of the birth canal to trauma, in doing so increasing the risk of HIV transmission.

The authors suggest that vitamin A deficiency may contribute to the higher rates of mother-to-child transmission reported in Africa (20-40% compared with 15-20% in Europe and Africa). They suggest that "improving vitamin A during pregnancy may lower vertical transmission rates of HIV" and that "Nutritional intervention may be a practical, inexpensive, and widely applicable option".

- 1. European Collaborative Study (1994), Caesarean section and risk of vertical transmission of HIV-1 infection, Lancet, 343, pp.1464-67, 11 June.
- 2. US public health service task force on the use of zidovudine to reduce perinatal transmission of human immunodeficiency virus (1994), Recommendations, Morbidity and Mortality Weekly Report, 43, RR-11, 5 August.
- 3. Semba, RD et al (1994), Maternal vitamin A deficiency and mother-to-child transmission of HIV-1, Lancet, vol.343, no.8913, pp. 1593-1597, 25 June.

Younger people have better chance of long term survival

A study carried out at the Royal Free Hospital in London has estimated that 25% of people with HIV will remain free of AIDS for 20 years after becoming infected with the virus, and that 18% will live for 25 years without developing AIDS.

The same study also suggests that younger people have a better chance of long term survival free of AIDS, with 32% of those infected under the age of 15 expected to survive without AIDS for more than 20 years. These estimates were based upon on a cohort of haemophiliac men with HIV. The extent to which these estimates apply to people infected in other ways remains uncertain.

Phillips, AN et al (1994), Use of CD4 lymphocyte count to predict long term survival free of AIDS after HIV infection, **British Medical Journal**, 309, pp.309-313, 30 July.

Child infected with HIV in hospital

A newborn child in the US is believed to have been infected with HIV while in hospital. The infant was admitted to hospital for a serious eye infection, and 8 months later he was found to be infected with HIV after being diagnosed with *Pneumocystis carinii* pneumonia. His parents and other carers all tested negative for HIV.

While in hospital, the child had undergone 99 procedures involving the use of needles or contact with mucous membranes, and there were 32 one hour periods during which the same health care workers performed procedures on both the infant and a child with AIDS in the same unit.

Although the source of HIV infection has not been determined, it seems likely that infection occurred as a result of patient-to-patient transmission. As the authors of the study conclude, this case "reinforces the need to adhere to universal precautions to prevent the spread of blood-borne pathogens in health-care settings".

Blank S et al (1994), Possible nosocomial transmission of HIV, Lancet, 344, pp.512-14, 20 August.

NEW PUBLICATIONS

- Naomi Honigsbaum, Children and Families Affected by HIV in Europe: the way forward (National Children's Bureau, 1994). Report of a symposium which brought together experts from eight European countries, including recommendations from a child and family-centred perspective on health and social services, substitute care and schooling (from Book Sales, National Children's Bureau, 8 Wakley Street, London EC1V 7QE, price £5.00 or £3.50 to Bureau members, plus postage and packing).
- Lorraine Sherr (ed.), AIDS and the Heterosexual Population (Harwood, 1993). This text "is an attempt to present a comprehensive examination of the psychological and sociological ramifications of HIV disease" in "the heterosexual population". Chapters likely to be of particular interest to ChildAIDS readers include "The challenge of AIDS in children", "Adolescents" and "The family and HIV disease". Order from booksellers, price £12.00 soft cover, £34.00 hardback.
- Department of Health Social Services Inspectorate, Women and HIV (1994). This report aims to help social services departments to review their assessment processes and planning of service delivery to better meet the needs of women affected by HIV. It includes sections on pregnant women and on child care needs. From: DH Store, Health Publications Unit, No 2 Site, Manchester Road, Heywood, Lancs OL10 2PZ.
- · Philip A Pizzo and Catherine M Wilfert (eds.), Pediatric AIDS: the challenge of HIV infection on infants, children and adolescents (Williams and Wilkins, 1994). A revised second edition of this huge textbook (over 1000 pages), with 55 chapters covering epidemiology, transmission, diagnosis, clinical manifestations, medical management, and social aspects (the latter mainly reflecting the US experience). As well as being an important medical reference book, there are some excellent and thought-provoking sections on speaking with children and families and on children speaking about HIV.

"I have AIDS and everyone is different than I am. It feels terrible to have AIDS because my tummy hurts a lot, and because if my friends find out, they wouldn't want to play with me. When I told the kids at school I had AIDS they made fun of me. I told them by accident. Now I want to run away from school. I wish I were not an AIDS patient. I wish I did not have to take medicine"

(Tanya, aged 6, one of the children quoted in Pediatric AIDS).

- · HIV Infection and AIDS: information and guidance for all providers of day care for children (Surrey County Council, 1994). Produced by social services with playgroup, childminding and nursery organisations, this booklet includes guidance on confidentiality, hygiene and other aspects of good practice. Produced by Quality Audit Team, Surrey Social Services, AC Court, High Street, Thames Ditton, Surrey KT7 0QA.
- · HIV and Children: a guide for carers in the voluntary and statutory services (East Sussex Health Authority, 1994). Booklet for people caring for HIV infected children and their families, covering such issues as the impact of HIV on the family, the needs of children, and hygiene (from Health Promotion Centre, Ivory Place, Morley Street, Brighton BN2 20E, tel. 0273 696011).
- · Trish McFarlane, HIV/AIDS: some issues for family and child care (DHSS Northern Ireland SSI, 1994). Written by a social worker in Belfast, this discussion paper looks at such issues as adoption, childminding and confidentiality in a Northern From: Social Services Inspectorate, Dundonald House, Upper Ireland context. Newtownards Road, Belfast BT4 3SF (0232 520500)
- · Refugee Council, Counselling, Care and Support for Refugee Women and Children Affected by HIV/AIDS (1994). Report of a seminar held in July 1994, with contributions on the needs of refugee women and children, African women, and HIV services for Asian and Middle Eastern women. From: Refugee Council, 3 Bondway, London SW8 1SJ.

• Living Positively: caring for children infected or affected by HIV

This video was commissioned jointly by Lothian and Strathclyde Social Work Departments, and focuses on care and support issues in relation to children and HIV/AIDS. Its prime use would be as part of a training programme on HIV/AIDS for foster carers and social work staff, though it also has relevance for other agencies working with families affected by HIV. The video is accompanied by a booklet which focuses on the key issues.

Available from: Lothian Regional Council Social Work Department, Room 428, Shrubhill House, Leith Walk, Edinburgh EH7 4PD, price £75 + VAT).

- The National Association for the Education of Sick Children has launched a newsletter, covering hospital teaching and home tuition of sick children and associated issues. A subscription costs £10 for 5 issues (from: NAESC, 18 Victoria Park Square, London E2 9PF).
- The summer 1994 issue of AIDS Action, the international newsletter on AIDS prevention and care, focuses on sex education and HIV prevention with young people worldwide. Details from AHRTAG, Farringdon Point, 29-35 Farringdon Road, London EC1M 3IB (tel. 071 242 0606).
- The launch of the HIV and AIDS in primary and middle schools World AIDS Week 1994 Project Support Pack was greeted with headlines such as Sex quiz... for seven-year-olds in the Daily Mail and other papers. The pack has produced by South been Warwickshire Health Promotion Department to help local schools to incorporate HIV and AIDS appropriately in their school curriculum. It includes a series of exercises developed with Year 7 children (aged 11 and 12) and suggested that these exercises could be adapted for use with younger children, although there is actually no mention of seven-year-

South Warwickshire Promotion Department, Tachbrook House, Tachbrook Road, Leamington Spa, Warwickshire CV31 3EQ (tel. 0926 452021).

EVENTS

3 November 1994, Talking to children about HIV, London. Workshop for women affected by HIV at the Positive Place Women's Group. Details from Sarah (081 694 9988) or Maggie (071 783

7 November 1994: ENB N57- course for healthcare professionals on care of families and children affected by HIV/ AIDS, London. 10 day module at Mildmay Hospital; call the education liaison secretary on 071 739 2331.

14 November 1994: Association for children with life-threatening or terminal conditions and their families national conference, Bristol. Programme from Nicky King, ACT, 65 St Michael's Hill, Bristol BS2 8DZ (tel. 0272 221556).

28 November 1994: Planning HIV services for children and familieslooking to the future, London (see page

30 November 1994: Year of the Family: the ripple effect of HIV (4th prisons and HIV conference), Harrogate. Details from Fay Addyman, Northern and Yorkshire Regional Health Authority (tel. 0423 500066).

1 December 1994: World AIDS Day: AIDS and the family. Various events worldwide.

23 January 1995: Working with HIV positive mothers and their children, London. Training by Positively Women, call Emily Doyle (071 700 0100, ext.274).

20 February 1995: ENB N57, Mildmay Mission Hospital (see 7 November 1994).

20/21 April 1995, Childcare workers and HIV, Edinburgh. Two day course organised by the Paediatric AIDS Resource Centre, 031 536 0806.

Free HIV/AIDS Training

PACE has been funded by the North Thames Regional Health Authorities to provide free training for any interested voluntary organisations and community groups in the North Thames region. Among the courses they can provide are "Issues for young people", "Families and children" and "Caring for the carers". Other course can be devised to suit a group's particular training needs. Further details from Peter Tamm, PACE, 34 Hartham Road, London N7 9JL (tel. 071 700 1323, fax. 071 609 4909).

HIV and child sexual abuse

CHILD SEXUAL ABUSE AND HIV/AIDS: a health and social needs assessment

Angela Thomas (Barnardo's) summarises her Wakefield study:

his study was initiated as a joint I venture between Barnardo's (with support from Children in Need) and Wakefield Healthcare, following concerns raised about the links between child sexual abuse and HIV in the Wakefield area. The sensitive and emotive nature of these links very quickly became apparent.

The study was conducted over a twelve month period. Information came from external sources, a review of the literature currently available, individual and group interviews with workers involved in the fields of child sexual abuse and/or HIV and information provided by a small number of survivors of child sexual abuse.

The response to the study reflected a wide spectrum of opinion. Some workers saw the issue as having little relevance to their everyday practice and others saw it as an important but largely unaddressed issue. Some workers feared that the sensational overlay which frequently accompanies HIV issues might obscure the other very real needs brought about by the abuse and others appeared shocked by the possibility and admitted to never having considered the issue. Young people made their wishes for openness and information with which to make choices plain, but at the same time some demonstrated their vulnerability and continued need for support. Reconciling these varied opinions and examining the reality of the situation in a suitably objective manner was one of the challenges of the work.

Little conclusive information upon the subject exists but it has been possible to establish certain facts. Research in the USA has demonstrated that child sexual abuse as a transmission route of HIV can and does occur. It is impossible, at present, to quantify the risk of this happening and indeed several variables may influence the outcome, most especially prevalence rates for HIV in a particular area.

It seems that low prevalence rates for HIV infection in Wakefield Metropolitan District presently make the possibility of HIV infection by this transmission route extremely low, however the existence of know HIV+ abusers in other parts of Britain indicates that complacency should be avoided. The potential for one HIV+ abuser to infect many children remains.

Certain young people are expressing concerns about HIV infection following sexual abuse. This is happening at a national level and at a local level, and there are indications that some of these concerns may remain unvoiced.

It has long been accepted that child sexual abuse can have harmful effects in later life. There is evidence which shows that for some victims of child sexual abuse there may well be adverse behavioral outcomes which may increase the possibility of infection with HIV.

The research has demonstrated the complexity of the considered issues with areas relating to HIV testing and confidentiality, issues relating to the abuser, and young people's participation in decision making processes being highlighted. The wider issue of promoting sexual health to vulnerable young people, many of whom may well have been sexually abused, in non-stigmatised accessible locations has also been highlighted.

In terms of the total picture of the child sexual abuse scenario it seems that HIV is one of several concerns which may appear post-disclosure. To deny their existence would appear to be as remiss as allowing them to totally dominate the agenda.

How to take account of this aspect of child sexual abuse and respond in a balanced manner is a challenge to those presently delivering services, particularly as it seems likely that such concerns will increase along with prevalence rates for HIV and growing public awareness. Recommendations which it is hoped will be of assistance in this task are contained in the report.

The report Child Sexual Abuse and HIV/AIDS: a health and social needs assessment is available from Lena Horner, Wakefield Healthcare, White Rose House, West Parade, Wakefield, West Yorkshire (tel. 0924 814400).